

MORTALITY DATA AND RECOMMENDATIONS FROM MORTALITY REVIEW (OCTOBER – DECEMBER 2011)

The following issues were identified during mortality reviews completed during the second quarter of fiscal year 2012 (October-December 2011). While the data presented may pertain to comorbid conditions that are not attributable to the cause of death, the risk involved with these conditions warrant further examination. It is hoped that this communication will lead to an increased awareness of the issues discussed and that this knowledge will translate to individual and systemic actions intended to reduce recurrence.

This communication is not intended to provide specific medical recommendations and interested parties should seek further clarification from trained medical professionals.

Identified Issues

Medication Administration Record (MAR)

Weight Gain/Loss

Recognizing and Responding to Changes in Status - “JUST NOT RIGHT”

Risk Plan

Fall Prevention Plan

Transition

Choking Prevention - Food Items that Need Extra Attention

Ensuring Safety During Bathing Activities for a Person who has Seizures

Internal Review of Death

Various Health Categories per Level of IDD and Cause of Death per Setting

Summary

References

References include, but are not limited to:

IAC 460 Article 6-10-10 Quality Assurance and Quality Improvement System;

IAC 460 Article 6-14-4 Training;

IAC 460 Article 6-16-3 Policies and procedures documentation;

IAC 460 Article 6-19-6 Monitoring of Services;

IAC 460 Article 6-25-2 Coordination of Health Care;

IAC 460 Article 6-25-10 Investigation of Death;

DDRS Policy: Personnel Records;

DDRS Policy: Requirements and Training of Direct Support Professional Staff.

Resources

Each person's primary care physician/specialist is another excellent resource for obtaining and developing plans for situations unique to each person.

There are many relevant websites available. A small sample of these include:

<http://www.rxlist.com/script/main/hp.asp>

<http://www.in.gov/fssa/ddrs/2635.htm>

<http://www.in.gov/fssa/ddrs/4066.htm>

<http://www.in.gov/fssa/ddrs/3948.htm>

Medication Administration Record (MAR)

This quarter, some of the mortality review discussion revolved around medication administration issues and/or medication errors. Some examples of identified issues include 1) inadequate system to ensure medications that were to be discontinued were indeed discontinued; 2) inadequate system to ensure medications that were to be started were started in a timely manner; 3) inadequate system to ensure that both the brand and generic medication were not being administered for the same diagnosis (creating a situation where the person was receiving a double dose); 4) risk plans were not in place when there were significant side effects to a medication; a person who self-administered medication (and the people who assisted) were not knowledgeable of the reason the medication was prescribed; and 5) the medication administration record did not accurately reflect the correct route (by mouth, via g-tube), for all prescribed medications.

The Mortality Review Committee recommended sharing the following suggestions with providers, case managers, and other stakeholders.

Medications administered on a daily basis are prescribed for a specific diagnosis determined by a physician (i.e., primary care physician, specialist, or psychiatrist). It is recommended that the Medication Administration Record include the diagnosis for any prescribed medication and/or treatment. When the diagnosis is included on the MAR, the association between the diagnosis and the prescribed medication is evident. This assures all concerned (e.g., primary care physician, nursing staff, direct support professionals, house managers/supervisors, health paraprofessionals, families, etc.) that the person's medication regimen has been reviewed and includes no "unnecessary" medication that is administered on a routine basis. Having the diagnosis(es) associated with each medication, allows the team to group medications by purpose (e.g., all psychotropics can be grouped according to the psychiatric illness(es) being treated, etc.). The team can more readily identify polypharmacy for psychiatric care along with other medical diagnoses such as hypertension. Staff should be knowledgeable about the name of the medication (brand and generic) along with the purpose of the medication and the potential side effects. This would not necessarily include PRN medications which are often used in comfort care for minimizing signs and symptoms of an illness.

When the MAR includes a brief list of potential side effects for a medication, the information is convenient to assist staff in knowing what to observe for side effects. When a medication has significant side effects, the team can use this information to develop an individual-specific risk plan regarding the medication. Risk plans can be generated based on polypharmacy use and side effect profiles.

For people who self-administer their medication, listing the diagnosis associated with the medication allows sharing of important information between the direct support staff and the person receiving services. Including the diagnosis on the MAR provides staff an opportunity to match the person's understanding of the reason for the medication with the information on the MAR, reducing opportunities for confusion or misinformation.

During this last quarterly period, there was an average of 671 medication errors reported each month. As can be seen in Table 1, the most frequent medication errors reported were associated with a person not receiving their medication (e.g., missed medication). This accounted for 68% of all medication errors reported during the month of December.

Table 1. Medication Errors Reported per Month

Description	Mar-11	Apr-11	May-11	Jun-11	Jul-11	Aug-11	Sep-11	Oct-11	Nov-11	Dec-11	Average 3/11 - 12/11
Total Medication Errors	618	711	715	662	688	758	658	668	673	672	682
Medication error jeopardizing health and safety and requiring medical treatment	2	0	0	0	1	0	0	2	3	2	1
Medication error, missed dose	445	528	503	478	458	527	446	450			479
Medication error, wrong dose	130	148	175	143	190	184	182	180	172	130	163
Medication error, given outside window									19	20	20
Medication error, missed, not given									442	455	449
Medication error, wrong medication	41	35	37	41	37	47	30	34	37	65	40
Medication error, wrong route	0	0	0	0	2	0	0	2	0	0	0

Weight Gain/Loss

This quarter, some of the mortality review discussion revolved around unintentional weight gain and/or loss. One example includes a person who lost a significant amount of weight within a few months. When asked for a copy of the person's weight log (or other documentation used to track weights for the previous 12 months), the agency indicated weights were not tracked since there was not a physician's order.

When a person experiences an unintentional weight gain or loss, it can be a symptom of a medical problem. It is recommended that if a person has a weight gain/loss of 5% in one month, 7.5% in 3 months, or 10% in 6 months, the agency creates a weight log for that person. Please be aware that a physician's order is not required to track a person's weight. If the person already has a weight log, it is recommended that more frequent weights be documented. Staff should be trained on how to take weights (e.g., same time of the day, same scale, same basic clothing items, etc.), where to document, who should be notified, when they should be notified, and how they should be notified of the weights. Staff should know who is responsible for sharing the information regarding the weight gain/loss with the health care professional.

Examples of weight logs are available at:

- [http://www.in.gov/fssa/files/Weight_Tracking_Sheet_OR-FN-HS-WG-60\(11-9-09\).pdf](http://www.in.gov/fssa/files/Weight_Tracking_Sheet_OR-FN-HS-WG-60(11-9-09).pdf) or
- [http://www.in.gov/fssa/files/WEIGHT_SHEET_OR-FN-HS-WG-58\(11-9-09\).pdf](http://www.in.gov/fssa/files/WEIGHT_SHEET_OR-FN-HS-WG-58(11-9-09).pdf)

Recognizing and Responding to Changes in Status - "JUST NOT RIGHT"

Many people are not able to tell us with words how they feel or what exactly is bothering them. But, they can and do frequently tell us by a change in the way they act or the sounds they make. Often, it is the direct support staff person who knows the person the best and is able to pick up small changes that could be signs of illness. When such changes happen direct support staff often describe the person as "not right," "something is wrong," "not themselves." How the change is described to a physician will make a difference in the physician's ability to understand the value of the observation, identify the problem is, and treat it.

When you notice that someone is not right, it may be helpful to think about describing your observations by comparing them to how the person usually behaves or appears. When you look at the person or think about what you are seeing, what is different from what you usually see?

- Does he/she have a different **look on their face**? Tired, afraid, in pain?
- Are they sitting or **moving differently**? Protecting a hand or foot, refusing to take a position that is normal for him/her?

- Is there a change in the type of **sounds** he/she is making? Are they more highly pitched? Or perhaps he/she is not making any sounds at all.
- What is his/her **temperature**?
- What is his/her **breathing** like?
- What is his/her **color** like? Pale or red? Blue around the lips?
- Have you seen this before? If so, when? What was going on?
- Has there been a recent **new medication**, adjustment to medication, or diagnosis that might help explain the change?
- Sometimes a **significant change** in a person's life or relationships will cause behavioral or physical signs. Has there been a death or loss of a person or a change in a routine?
- Is he/she eating and drinking? If so, is this different than his/her usual pattern?
- Is there a change in his/her bowel or bladder habits?
- Has there been a change in his/her willingness or ability to participate in activities?
- When did you notice this change? Did it just start today, or has this been a gradual change?

IF YOU NOTICE CHANGES, WHAT SHOULD YOU DO?

Call 911 if this happens:

- The change is very sudden
- The person looks very sick
- The person won't wake up

In other situations:

- Call or talk to your supervisor or nurse about what you see or hear
- Write down what you see or hear and share the information with other staff.
- Talk about what you see and hear with other staff and write down what they report
- Make a physician appointment
- Keep notes of what you see and hear and bring them with you to the doctor's appointment to assist the physician in diagnosing the problem.

Courtesy of Massachusetts DMR

Links to fact sheets regarding Recognizing and Responding to Changes in Status are:

- http://www.in.gov/fssa/files/recognizing_change_in_status.pdf
- http://www.in.gov/fssa/files/responding_to_change_in_status.pdf.

Risk Plan

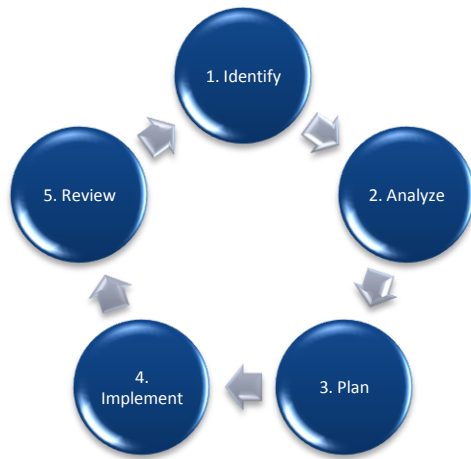
A recurring theme identified through mortality review is the lack of individual-specific risk plans for some or all of a person's identified risk issues.

A risk plan is a written set of guidelines and instructions that focus on identified medical/behavioral concerns of the person, providing clear steps to be taken by everyone who is supporting the person receiving services. When a risk issue (i.e., health or behavioral problems that can be harmful if not handled appropriately) develops or changes at any time of the year, the team should ensure the risk plan is updated timely and appropriately. Once the risk plan(s) are updated, it is important that providers reference the date reviewed/revised on the plan to assure training and

implementation of the correct plan(s). Recommended components include identification of risk issues, development of a risk plan, implementation of a risk plan (including training of appropriate people in all locations), and monitoring of the risk plan. If an event occurs despite already having a risk plan in place (e.g., a person falls despite a fall prevention plan or a person chokes despite a dining plan/choking risk plan), the team is expected to meet urgently to review the event, identify the reason the plan failed, and amend the plan to improve effectiveness in preventing or minimizing the risk.

Risk management consists of several action steps and is a dynamic process (Figure 1). A risk issue is identified, potential strategies are analyzed, and a plan is developed. From there, training on the individual-specific risk plan is completed and the plan is implemented in all applicable settings. Review of the effectiveness of the plan is completed and the cycle continues including revisions to the plan, additional staff training, etc. as needed to ensure maximum effectiveness.

Figure 1. Risk Management Cycle



Fall Prevention Plan

If a person has a history of falls (with or without injury), a fall prevention plan should be developed and implemented. There are numerous causes for falling (e.g., environmental (slippery floors from a spill), ill fitting clothes (trousers too long), worn shoes, unsteady gait, etc.) As a person gets older, physical changes (e.g., poor vision, postural changes, etc.) and health conditions (e.g., de-conditioning after prolonged bed rest, cardiac conditions, neurological conditions, etc.) — and sometimes the medications used to treat those conditions — make falls more likely. Falls are a leading cause of injury (and in some cases a contributing factor leading to death) among older adults.

Staff should be aware the person is a fall risk and be trained on the individual-specific fall prevention techniques. Staff in all locations (e.g., home, day program, etc.) should be trained on the fall prevention plan. While it is good for staff to know general fall prevention techniques, it is important that the fall prevention plan include fall prevention techniques that are specific to the person. For example, if the person uses a walker in certain situations, the fall prevention plan should specifically state when the walker is to be used. Another example is a person who needs assistance in transfers. The fall prevention plan should include information such as how many people are needed to do a safe transfer, what prompts are needed, what methods have been determined to be safe, etc.

With the update to the DDRS Incident Reporting and Management Policy (in the 3rd Quarter FY11), falls associated with any injury became a reportable category (only those associated with significant injury, ER visit and/or admission reported prior to this). Following this change, the number of reported incidents in this category increased significantly (Table 2).

Table 2. Number of Incident Reports of Falls with Injury per Quarter

Description	4Q FY08	1Q FY09	2Q FY09	3Q FY09	4Q FY09	1Q FY10	2Q FY10	3Q FY10	4Q FY10	1Q FY11	2Q FY11	3Q FY11	4Q FY11	1Q FY12	2Q FY12	Average (15 quarters)
Falls with Injury	533	532	455	435	479	568	479	496	559	559	572	716	1277	1275	1024	664

Transition

Prior to transitioning to a new home, risk plans should be in place and staff trained on implementing them. It is recommended that the outgoing direct support staff write down subtle changes they notice when there is a change in the health status of the person (e.g., when he/she is not feeling well). These subtle changes should be shared with the new staff. Risk plans should be updated by nursing staff, behavioral staff, dietary staff, and other clinical staff. Updating of behavioral plans, including updated trends and data collection, types of data collected, and tools used in collecting the data before the move, are essential for a successful transfer. These risk plans provide an opportunity for those who know the person to write concise steps, as well as include preventive steps that have proven helpful in the past. It may be helpful in guiding the new team to include information concerning which steps had no effect or did not work.

Some examples pulled from review of mortality packets include the following. Some of the more common risk plans that are critical for anyone working with/providing services for a person with IDD to be aware of and trained on prior to day 1 of providing supports/services include dining plans, choking prevention plans, pica prevention plans, behavior support plans, seizure management plans, elopement prevention plans, fall prevention plans and bowel management plans. If the person receiving services has any of these risks, staff need to be trained in advance or as the person arrives. Any delay in training and risk plan creation increases the risk to the person receiving services.

Choking Prevention - Food Items that Need Extra Attention

Certain food items have the potential to block the airway due to shape and/or texture. A few of these are hot dogs, marshmallows, grapes, and peanut butter. The skin of such items as hot dogs and grapes can lead to choking if not cut in all directions/dimensions according to the needs of the person. If hot dogs are to be served, they might need to be cut lengthwise in order to interrupt the circle of skin, as well as cut into small width chunks, depending on the needs of the person. Similarly, grapes should be cut in two or more pieces to allow the skin to be chewed when it has already been cut into small pieces.

There is a wide variation in the term “bite size” and this term should not be used without providing more clarification. Different people may interpret this term differently. Bite size is generally either one inch cubes or one-half inch cubes, or defined by clear visual examples, such as the size of a quarter, a dime, etc. There should be a graphic illustration of a one inch cube, quarter, etc. to verify the size which is acceptable. A speech language pathologist can assist in these important details and training of staff.

There were three deaths due to asphyxiation (associated with food/pica/objects/medication) this quarter (2Q FY12).

Choking Episodes Requiring Intervention: There were 65 reports submitted in the second quarter of FY12 (October through December), above the quarterly average of 52, and the second quarter showing an increase from the previous quarter (Table 3). This quarter (2Q FY12), there were two districts (Districts 7 and 8) that had zero choking incidents reported for at least one of the months included in this quarter's data (12/2011 for District 7 and 10/2011 for District 8).

Table 3. Number of Choking Incidents Requiring Intervention per Quarter

Description	4Q FY08	1Q FY09	2Q FY09	3Q FY09	4Q FY09	1Q FY10	2Q FY10	3Q FY10	4Q FY10	1Q FY11	2Q FY11	3Q FY11	4Q FY11	1Q FY12	2Q FY12	Average (15 quarters)
Choking requiring Intervention	60	71	58	48	59	38	40	42	50	50	49	51	43	55	65	52

The Choking Checklist is available at http://www.in.gov/fssa/files/Choking_Checklist.pdf. The checklist is useful when developing and/or reviewing/revising a risk plan. In addition, individual-specific training regarding this risk area can incorporate pertinent information from the checklist.

Internal Review of Death

Seventeen of the forty (42.5%) mortality review packets reviewed by Mortality Review Committee for people who received services from a funding source other than nursing home this quarter did not include an internal review of death. Per *DDRS Mortality Review Policy*, an internal review of a person's death should be completed regardless of the place of death (e.g., home, hospital). This policy can be found on the DDRS website at <http://www.in.gov/fssa/ddrs/3340.htm>. Relevant agency policies/procedures, individual-specific risk plans, and staff training on the individual-specific risk plans should be included as part of the mortality review packet.

Internal reviews of death should be completed in a timely manner (see *Mortality Review Policy* effective 5/30/11). Given that autopsy results can sometimes take weeks to receive, and there may be delays and obstacles in obtaining EMS and hospital records, a timely initial internal review according to the policy is expected. If information/reports remain outstanding, a list of outstanding documents and the last date(s) of contact can be included with the review. Upon receipt of the outstanding documents, a final report can be generated and forwarded.

Ensuring Safety During Bathing Activities for a Person who has Seizures

Drowning from a seizure in a bathtub represents a small, but potentially preventable, proportion of all deaths by drowning. It is recommended that providers ensure a bathing assessment is completed for any person with a seizure disorder. If a person has uncontrolled or poorly controlled seizures, his/her blood levels are not in a therapeutic range, or if the person is in a dazed state, extra precautions should be taken. It is recommended that the provider agency establish a bathing/showering protocol that could include, but is not limited to: All consumers diagnosed with a seizure disorder must have one-on-one supervision while in the bath or shower. It may be acceptable for the consumer to draw the bathroom shower curtain to ensure privacy. At no time, is the staff to leave the consumer unattended in the bathroom during bath/shower time. If the home is not fully staffed at bathing/showering time, the bath should be given earlier or later (when the home is fully staffed). In addition, all consumers who are unable to sit up unassisted in the tub or call for help when needed, will be required to have one-on-one assistance that follows the protocol. If, at any time, a change in the health status of the consumer occurs, a bathing assessment will be required to be completed or updated, risk plans updated, staff trained, and protocol implemented as needed. Staff should be trained on the bathing/ showering protocol.

Pertinent links:

- Health and Safety – Seizures and Bathing Fact Sheet [http://www.in.gov/fssa/files/reminder -
_seizures_and_bathing.pdf](http://www.in.gov/fssa/files/reminder_-_seizures_and_bathing.pdf)
- [http://ddsn.sc.gov/providers/manualsandguidelines/Documents/HealthCareGuidelines/NursingMgmtSeizures.p
df](http://ddsn.sc.gov/providers/manualsandguidelines/Documents/HealthCareGuidelines/NursingMgmtSeizures.pdf)
- <http://www.epilepsy.org.uk/info/safety>

Various Health Categories per Level of IDD and Cause of Death per Setting

Through an exploration of mortality incidents reviewed from 10/1/2008 through 12/31/2011, we are able to identify patterns and associated recommendations.

Table 4 provides information concerning diagnoses common at various levels of IDD. GERD occurred in over one-third (range per decade - 35-45%) of all those that died at each level of IDD. Similarly, dysphagia was a common comorbid condition at each level of IDD. The diagnosis of CVA was more likely to be a comorbid condition with those that had mild, moderate, or severe IDD, than in the borderline or profound IDD population. Additional data of note:

- Those with borderline IDD that died had associated comorbid diagnoses (dementia in 24% at time of death, dysphagia in 33% at time of death, CVA in 8% at time of death, GERD in 40% at time of death, and hypothyroidism in 24% at time of death).
- For those with mild and moderate range of IDD, at the time of death GERD was the most commonly associated comorbid condition tracked (present in 39% of people with mild IDD, and 44% in those with moderate IDD at the time of death).
- For those with severe IDD, comorbid diagnoses with a prevalence of 30% or greater at the time of death included dementia, dysphagia, GERD, and seizures.
- For those with profound IDD, at the time of death comorbid conditions associated with 30% or greater prevalence included G tube placement, dysphagia, GERD, and seizures.

Because of the frequency in which these conditions occur in the IDD population, it is recommended that staff be provided initial in-service training and on-going review of these conditions. Trained staff with a better understanding of these conditions and knowledge and skills to care for the person with these conditions would translate into improved quality of care, as well as improved communication with other staff and the health care coordinators and health care providers. Likewise, education concerning early signs and symptoms may assist in identifying these conditions at an early stage and allow early treatment, with resulting improved quality of life.

TABLE 4. VARIOUS HEALTH CATEGORIES PER LEVEL OF IDD - deaths reviewed by MRC 10/1/08 to 12/31/11 (Percentages calculated horizontally)										
Level of I/DD	Total Number of Deaths	Various Health Categories								
		Dementia	G tube	Down's	Dysphagia	CVA	GERD	Hypothyroidism	Sleep Apnea	Seizures
Borderline	103	24%	20%	1%	33%	8%	40%	24%	13%	23%
Mild	371	27%	12%	8%	27%	11%	39%	25%	9%	35%
Moderate	227	30%	14%	22%	33%	12%	44%	27%	7%	35%
Severe	181	39%	26%	28%	45%	10%	40%	28%	8%	46%
Profound	335	21%	41%	13%	52%	7%	45%	26%	6%	57%
Unknown	31	39%	26%	19%	32%	3%	35%	19%	3%	26%
Total	1248	28%	23%	15%	38%	9%	42%	26%	8%	41%

Because the DD waiver setting and the nursing home setting were the most common residency setting for people with IDD at the time of death (these two settings combined were home to 79% of the individuals at the time of death), the causes of death that were tracked mainly occurred in these two settings (Table 5). For deaths due to cardiovascular disease, respiratory causes, cancer, and sepsis, most occurred in these two settings. However, the percentage proportion from these deaths was not always similar to the percentage of total deaths in these settings. For instance, the DD waiver setting was the home to 26% of all IDD deaths, but 36% of all sepsis deaths occurred in the waiver setting. The reason for the increased percentage of sepsis deaths in this setting could not be determined. Similarly, 33% of all cardiovascular deaths occurred in the DD waiver setting. For these two causes, this could mean an over-reporting of deaths due to these causes (e.g., a person found deceased in bed in the morning, is at times signed off as a myocardial infarction), or the other settings could be under-reporting the causes of death or using terms assigned to other categories of death (e.g., died of a UTI rather than urosepsis).

These data were also consistent with the interpretation that early health status changes leading to a cardiovascular cause (breathlessness due to worsening heart failure, increasing angina and discomfort which may be difficult for a nonverbal person to communicate) or to sepsis (hypotension, anorexia, ataxia, pallor, cyanosis, fever, vomiting) were not identified at the early stages of clinical presentation. Ongoing in-service training for health status changes is important, and should be considered at periodic intervals to reinforce the information to the direct support staff. It is recommended that provider agencies review the causes of death according to the categorized setting (DD waiver, etc.), and also review the illnesses that occur frequently or periodically. A review and adaptation of the training curriculum to meet the needs of the individuals and agency staff should be considered.

**TABLE 5. CAUSE OF DEATH FOR EACH AGENCY SETTING - deaths reviewed
by MRC 10/1/08 to 12/31/11
(Percentages calculated vertically)**

Agency Setting	Total Number of Deaths	Cause of Death			
		Cardio-vascular	Respiratory	Cancer	Sepsis
DD	26%	33%	20%	24%	36%
SGL	11%	13%	10%	14%	14%
LP-ICF/MR	3%	5%	3%	1%	1%
SS	5%	6%	3%	5%	2%
Title XX	2%	3%	2%	2%	2%
Nursing Home	53%	39%	60%	52%	46%
SLI	0%	0%	1%	2%	0%
Total	1247	222	178	130	115

*27 unknown level of IDD; 1 terminated funding shortly prior to death
Information received after analysis therefore not included in above data
- Sepsis, 63 YO and 58 YO, both Nursing Home, 1 profound and 1 mild IQ,
remove CV for 58 YO (10/09 to 12/09)

Summary

A person's needs do not remain the same indefinitely; it is important for team members to have the knowledge to recognize the changes when they occur and to have the tools necessary to respond quickly and appropriately to reduce the risk.

It is suggested that provider agencies ensure the staff in the homes are trained on the comorbid conditions associated with the levels of IDD of the individuals in the home along with the early warning signs and symptoms of sepsis and the need to communicate changes in health status to the appropriate person for review and action.